



MEETING MINUTES
Rhode Island All Payer Claims Database
Data Release Review Board Meeting
Wednesday, January 27th 5:30 – 7:30 pm
Room 401, RI Department of Health
3 Capitol Hill, Providence, RI 02908
FINAL

Members Present:

Monica Neronha
Solmaz Behtash
Cory King
Betsy Stubblefield Loucks
Kenny Alston
Michael Lichtenstein
Lawrence Rothstein
Patrick Tigue
Kimberly Paull

Members Absent:

Ira Wilson
Amy Black

Staff Present:

Jennifer Wood, Deputy Secretary and General Counsel, Executive Office of Health and Human Services
Nicole Alexander-Scott, Director, Department of Health
Alyssa Ursillo, Freedman HealthCare
Samara Viner-Brown, Department of Health
Melissa Lauer, Executive Office of Health and Human Services
Jim Lucht, Office of Health Insurance Commissioner
Amy Zimmerman, Executive Office of Health and Human Services
Linda Green, Freedman HealthCare

1. Welcome and Introductions

The meeting was convened by Alyssa Ursillo, Project Manager for the RI APCD, at 5:35 pm. The Board members and staff went around the room and introduced themselves.

2. Discuss Meeting Schedule

Ms. Ursillo discussed establishing a regular monthly meeting schedule and canceling if there were no items on the agenda. No Board members expressed concern about this. Ms. Ursillo will send around a survey to find the best times for members.

3. Open Meetings Law briefing

Deputy Secretary Jennifer Wood briefed the Board on their responsibilities under the Open Meetings Law. The RI APCD team will be responsible for posting meeting agendas and minutes publicly, and posting an annual meeting schedule once it is determined. The Deputy Secretary informed Board members that there were no instances anticipated in which they would need to go into a closed session. She also discussed a “walking” meeting and the responsibility of Board members to not discuss matters that would come before the Board with each other outside of the public meetings. A Board member asked what happens if they miss a meeting but would like to comment on an issue. Ms. Wood responded attending telephonically or electronically is not permitted except in the cases of physical disability, but that they may submit a public comment to be read during the meeting. The APCD team will send out summaries of any data request applications in advance.

4. RI APCD Overview

Ms. Ursillo discussed the purpose of the meeting, which was to orient members to the APCD, discuss the role of the Data Release Review Board, and introduce the State’s plan for launching the APCD as the “HealthFactsRI” database beginning in February. She then led a presentation of the RI APCD to orient Board members, including an overview of APCDs nationally, the legislation and regulations passed to implement the RI APCD, its interagency governance structure, APCD goals, and available data.

Ms. Ursillo gave a detailed explanation of the privacy protections built into the APCD’s data collection structure, including that no direct patient identifiers are collected, and that members may opt out of the database at any time. She emphasized that no other state has this level of protection. Ms. Ursillo also reviewed the way these protections are implemented through the use of a Lockbox vendor that assigns a unique ID to each person and flags opt outs to allow payers to remove this information before sending data to the APCD. Ms. Wood emphasized that the unique identifier allows for longitudinal analyses of members across payers and time while still addressing privacy concerns that were raised during initial legislative hearings.

Dr. Rothstein asked how members were notified of opt-out. Ms. Ursillo clarified that all payers sent current members letters in 2014 (and any new members since then) notifying them of opt-out. If a current address could not be identified for the person, their data is not included in the APCD.

Ms. Ursillo also reviewed how data flows from the Lockbox vendor to the Data Aggregator, the Analytic vendor, and the State. Ms. Ursillo then reviewed the RI APCD privacy guidelines, including:

- Re-identification of members is prohibited and will be enforced through an agreement to terms and conditions for any data in which this is a risk.
- Any publications derived from APCD data must follow the CMS cell size suppression rule, in which any cell less based on less than 11 members, services, etc. cannot be displayed.

Ms. Wood emphasized that the Board will be exercising their professional judgement about whether there is a risk of re-identification and if an applicant’s data security or publication plans do not comply with the privacy guidelines.

Dr. Rothstein asked if there are any regulations around data breach for the vendors. Ms. Wood responded that the vendors must comply with state and federal regulations regarding the way the data is stored and they are all under BA agreements with the State.

Ms. Ursillo then reviewed the role of the Board, which is to evaluate the consistency of the request or file format with the RI APCD privacy guidelines and make a recommendation to Dr. Alexander-Scott. The Board will review the format of pre-determined analytic files to be available for download (or via FTP at first) from the Dept. of Health website and all requests for non-standard extracts.

Mr. Alston asked if there is a time requirement by which the Board must review an application and make a recommendation. Ms. Wood answered that this is not an environment of urgency, that the data is all retrospective, and that they should be deliberative and consider all public comments in making recommendations to Dr. Alexander-Scott. Ms. Ursillo clarified that applications will be posted to the state's website for public comment for 10 days. Dr. Alexander-Scott added that the role of the Board is distinct from an IRB and that the Board does not replace an institution's IRB for academic research.

The Board briefly discussed how to move recommendations forward to Dr. Alexander-Scott. Ms. Wood emphasized they can communicate minority and majority opinions to the Director. Dr. Alexander-Scott noted she would prefer to be fully informed. A chairperson will be appointed for the Board – Dr. Alexander Scott encouraged Board members to choose amongst themselves. A Board chair will be selected during the next meeting.

Ms. Ursillo reviewed the types of data elements included in the database, and the types of data products to be made available to the public. A Board member asked what the purpose of the fee was for certain data products. Ms. Ursillo replied it was to cover costs of producing the files and for sustainability of the project.

5. APCD Data Launch to Public

Ms. Ursillo outlined the plan for making data available to the public via aggregated reports and tables in February and detailed datasets in March. The database will be renamed as "HealthFactsRI", a more colloquial name for public marketing.

Mr. Lichenstein asked how the topics of the public reports were chosen and how they could get additional topics. Dr. Alexander-Scott noted these present an opportunity to tell a story of how valuable the data is. Ms. Paull noted it shows the value added beyond just storing the claims in a database. Ms. Lauer added that there will be several trained state users in each agency that will issue reports within their areas of expertise based on the data.

Ms. Ursillo reviewed the types of report dimensions and emphasized that cell sizes of less than 11 will be suppressed but are not anticipated in these public reports. She then noted that in March, more detailed datasets will be available for a fee. The Board will review the format of pre-determined extracts to be made available for download, as well as requests for member-level detailed extracts.

Ms. Loucks asked if there will be an evaluation of the process and the fee structure. Ms. Ursillo answered that user feedback will be solicited through webinars and user groups.

6. Public Comment

A member of the public asked whether applicants will need to be present at Board meetings when their application is being reviewed. Board members debated this and felt they could come before the Board either as a member of the public or if the Board would like to ask them questions. Members generally agreed this would help expedite the process. Ms. Ursillo noted there is no regulatory prohibition on this. Dr. Alexander-Scott suggested offering a process around this at the next Board meeting.

Ms. Neronha asked if there needs to be an intention to improve the overall health of the state for an applicant's request to be approved. The Board discussed this and generally agreed that their role was to evaluate the privacy protections and that the lack of public health benefit should not necessarily inhibit approval. However, if they feel the project would cause harm or would have no public benefit, this would be something to consider and include in their recommendation to the Director.

A member of the public from the hospital association asked if provider names would be included in the data being published in February. Ms. Ursillo answered no, not in the February reports. He also pointed out that hospitals spend a lot of money to submit a quarterly hospital discharge data set to the state and this seems redundant with the APCD. Ms. Green pointed out that while the hospital discharge data includes the uninsured, the APCD does not. The Board briefly engaged in a discussion as to whether or not hospital and free clinic data could be collected as part of the APCD. Ms. Ursillo was unsure if this would require a change in statute.

7. Next Steps and Adjourn

The Board will meet again on February 11th to review the format of Level 2 pre-determined analytic data sets. Ms. Ursillo will send out a survey to determine a regular meeting schedule.